



The PML survivor's handbook

A Journey of Resilience, Knowledge, and Empowerment

Edited by Luca Isabella

About

This little guide offers essential knowledge and practical strategies for individuals affected by Progressive Multifocal Leukoencephalopathy (PML), families, and healthcare professionals. From understanding the condition to navigating treatment and life after recovery, this guide provides a lifeline of support and guidance for all those impacted by PML.

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Date of publishing

2023

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While I have dedicated time and effort to create this manual, I have decided to offer it for free to ensure that information about PML reaches as many people as possible.

If you have found this ebook helpful, I kindly ask you to consider making a small donation to support my work and help me continue to provide valuable information on PML.

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Thank you wholeheartedly for your support and for being part of this important cause.



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Preface

In 2015, I began experiencing persistent headaches and severe fatigue, initially attributing them to work stress. Over time, additional neurological symptoms emerged, raising concerns, and prompting me to seek medical help. Subsequently, I was admitted to the hospital for further investigation.

Initially, doctors suspected ischemia, a condition characterized by reduced blood flow, as the cause of my symptoms. However, they weren't entirely convinced by this diagnosis. To gain more clarity, they did an MRI scan that revealed lesions that were interpreted as of a brain tumor.

To address the situation promptly, I was prescribed steroids and urgently transferred to another hospital for brain surgery. Unfortunately, the use of steroids seemed to worsen my condition instead of improving it. Further examination and evaluation were deemed necessary to fully understand my health issues.

At the new hospital, thorough medical tests were conducted, including a lumbar puncture. The results led to a revised diagnosis: PML (Progressive Multifocal Leukoencephalopathy). From that point onward, I received care and guidance from the infectious disease department.

For nearly ten months, I underwent various treatments and interventions while staying in the hospital. This period was exceptionally challenging as my symptoms rapidly progressed, affecting my mental faculties, vision, speech, coordination, and even causing paralysis. Coping with these symptoms and undergoing extensive medical care was a strenuous and trying journey.

Eventually, after months of hospitalization, my condition stabilized, and I was discharged. Though the road to recovery was

long and difficult, I'm grateful for the support I received from the infectious disease department and the medical team during this challenging time.

When I resumed reading, my first instinct was to connect with people who had experienced PML or were like me. I searched the internet in both Italian and English, hoping to find relevant information. Unfortunately, my search proved futile, as the available information was a mix of conflicting perspectives.

However, I stumbled upon a Yahoo group called "PML survivors and supporters." Immersing myself in years' worth of posts, I finally discovered the information I desperately needed. Most importantly, I no longer felt alone in my struggle with PML. Reading the stories of survivors gave me hope that my fate wasn't sealed, and there were individuals who had managed to overcome this devastating condition and live on for many years. I had found a small community — a "peer support" group.

After a year, the Yahoo group unexpectedly disbanded. In response, some former members, including myself, decided to create an information page on Facebook along with a private group. Although there is some information available online about PML, it's often either highly specialized or too general, mainly tailored to the United States. This creates a language barrier and makes it challenging for individuals outside the US to find relevant resources.

While my doctor provided me with sufficient information, managing the group made me realize that not everyone is as fortunate in receiving comprehensive support and guidance. Patients and caregivers from around the world reach out to join our group, and as survivors whose lives have surpassed five years

since diagnosis, we're always ready to offer information, reassurance, and practical advice.

It's important to note that we don't provide medical opinions and encourage individuals to consult their healthcare professionals. Nonetheless, we frequently receive gratitude for the invaluable support we provide, regardless of its magnitude.

Within our group, we encounter various challenges related to PML, including finding doctors trained specifically in PML, determining effective physical therapy and speech therapy methods, adapting lifestyles to cope with the condition, and exploring complementary therapies beyond medication. We also discuss ways to improve communication with physicians and the impact of social media and support groups on our overall care and quality of life. While survival outcomes may vary, we hold onto hope and aim to share our experiences to provide valuable insights.

The patient's perspective encompasses their perception of the impact of their health condition on their life, expectations of consultations and healthcare professionals, and treatment priorities. We advocate for the development, expansion, and promotion of patient associations to offer support to both patients and caregivers. Patient perspectives serve as vital sources of information for healthcare providers to better understand and address the diverse and complex needs of individuals living with PML.

Our mission is to raise global awareness about PML and the JC virus through educational initiatives. By increasing knowledge and understanding, we aim to improve the overall management and care of individuals affected by this condition.

Luca

PML Survivor

Introduction: What is PML

Progressive multifocal leukoencephalopathy (PML) is, in the general population, a rare but serious infection of the central nervous system (CNS). It results the reactivation of a common infection by a virus known as JC virus (abbreviated as JCV), and additional risk factors that include a weakened immune system and possibly genetic factors.

Prior infection with the JC virus is required for PML to develop. Antibodies against JCV are found in 50-70% of the general adult population, indicating prior infection, and in these people the virus will likely persist for life, but causing no obvious symptoms. Despite this high prevalence of JCV infection in the human population, the incidence of PML is very low.

The development of PML, while dependent on the presence of the JC virus, is the result of a failure from the immune system to keep JCV infection under control. This impairment of host immune function may occur in people with different conditions, including hematological tumors, such as lymphoma; therapeutic treatments that affect the immune system, such as immune suppressive therapies in transplanted people or in people with autoimmune disorders, or treatments with immunomodulant drugs aiming to control inflammation, such as in multiple sclerosis; HIV-infection; other conditions characterized by an abnormal immune control, such as idiopathic CD4 lymphocytopenia (ICL) or other congenital immune deficiencies. Indeed, the incidence of PML has increased in recent years due to the use of immunosuppressant or immunomodulant medications, such as natalizumab, used for treatment of multiple sclerosis, or rituximab, used to treat several tumors.

Although the mechanisms leading from a benign infection to such a severe disease as PML are not completely understood, there is evidence that, upon immune suppression, JCV escapes the host immune control and develops mutations in its genome that select for new viral variants with an advantage in terms of tropism and infection of brain cells. Thus, PML is eventually sustained by JCV genetic variants that are selected within an immunocompromised host. Finally, being PML such a rare disease, even in 'at risk' population, it is also possible that a genetic host predisposition plays a role in the chain of events leading to PML.

Initial symptoms of PML vary largely, depending on the site, number, and extension of the initial lesions, and are the result of a process of demyelination in the brain. These may include loss of language ability, changes in personality, memory loss, loss of coordination or clumsiness, vision problems, headaches, and seizures. Typically, the onset of symptoms is insidious, spanning up to several weeks. As the disease progresses, symptoms become worse, for example difficulties in hands movements may evolve into arms paresis, and severe disability or death will often result.

PML prognosis varies depending on several factors, including underlying comorbidities. If left unmanaged, the mortality rate is up to 50% within the first three months of diagnosis. In some cases, intervention can improve the chance of survival, although it is likely that some significant neurological deficits will be permanent.

Since PML results from an impaired immune system, the only available treatment options are based on reconstitution of such impairment. This can be achieved, in people receiving immunosuppressive or immunomodulant drugs, by stopping their administration, or, in persons with HIV infection, through initiation of anti-HIV treatment. However, many patients may not respond

to these approaches or not quickly enough to stop PML progression before development of severe deficits. Additional experimental immune-based approaches may also be used in some circumstances, but currently none of these has been shown to improve substantially PML outcome.

The diagnosis of PML and what to expect.

Diagnosing PML can be challenging because the symptoms can be like those of other neurological diseases. Additionally, PML is a rare disease, so it may not be considered as a potential diagnosis initially. Improved education and awareness among healthcare professionals and patients are crucial for early detection and effective management of this challenging condition.

To diagnose PML, doctors typically start by taking a thorough medical history and performing a physical exam. Physicians may use various diagnostic assessments, the most important being magnetic resonance imaging (MRI) scans and cerebrospinal fluid (CSF) analysis for JC virus DNA detection. In most of the cases the diagnosis of PML is achieved in the presence of a suggestive clinical history, for example the presence of a condition of immune deficiency and the subacute onset of neurological problems together with suggestive brain lesions at MRI, and it is confirmed by the evidence of JCV DNA in the CSF. Usually, a brain biopsy is not necessary to confirm the diagnosis. This involves removing a small piece of brain tissue and examining it under a microscope for signs of the JC virus. However, brain biopsy is an invasive procedure and carries some risks, so it is only recommended in certain situations.

Once a diagnosis of PML is confirmed, the next steps depend on the individual patient's symptoms and overall health. There are no known interventions that can adequately treat PML if it occurs. However, the reduction of an underlying immune deficiency, when possible, may help slow or halt the progression of the disease.

If PML is associated with certain medications, it is likely that your doctor will have to discontinue the use of these medications to

help restore the immune system. For patients with HIV, doctors may begin treatment with highly active anti-retroviral therapy. In some patients, particularly those with HIV and MS, it is possible that restoration of the immune system may cause an additional condition called immune re-constitution inflammatory syndrome (IRIS), which may itself lead to a decline in of patient condition and may lead to death or severe disability if not promptly recognized. If your doctor detects this, he or she will likely treat the inflammation inside your body.

In many cases, however, reduction of immune suppression cannot be possible, for instance on persons with congenital or other immune deficiencies, for example in the case of idiopathic CD4 cell lymphopenia, or ICL.

Anyone with a diagnosis of PML should immediately have their physician contact a reference center for PML in her/his own country, to receive the most accurate and updated information for standard and possibly supplemental experimental treatment approaches.

Apart from reduction of immune suppression, the treatment options for PML are limited, and there is no one-size-fits-all approach. Some drugs that were thought to directly inhibit the capacity of JC virus to replicate in the brain cells have been used in the past and some are still used in PML patients, based on the report of anecdotal success in individual cases: these include, among the others, mirtazapine (an antidepressant drug), mefloquine (an antimalarial drug), or cidofovir (an antiviral drug active against several other viruses). None of these drugs, however, is currently recommended for treatment of PML because there is no evidence in large studies and in the clinical practice that they may help mitigate or halt the disease. It is important to know that

there are recommendations against the use of some drugs, like cidofovir, whose toxic effects may be unacceptable.

In some cases, patients may also be candidate to receive experimental immune therapies to help boost the body's ability to fight the virus. Usually, patients are referred to reference centers that have some experience with such treatments. Current experimental options are represented by the infusion of cells obtained from a donor that have been stimulated to recognize the virus (also called “viral specific T-cells”), or by the administration of “cytokines” (molecules produced by human cells that regulate the immune processes), like interleukin-7, or of immune-check-point inhibitors (molecules used for treatment of several cancers that may make human lymphocytes more active against infections). However, there is currently no evidence that they could impact significantly on the outcome of PML.

The prognosis for PML varies widely depending on the individual patient's symptoms, overall health, and the response following reduction of immune suppression. Some patients may experience only mild symptoms and recover fully, while others may experience severe disability or even death. Some patients may experience a gradual decline in their physical and cognitive abilities, while others may experience more rapid progression of the disease. Also, although restoring the immune system may help in recovering from some PML symptoms, some of the serious effects of the disease are often permanent.

The impact of PML on patients and families

The disease has a profound emotional impact on patients and their families, who may struggle to come to terms with the diagnosis and to carry out daily life activities and with the uncertainty surrounding the prognosis.

One of the most challenging aspects of PML is the range of physical and cognitive symptoms that patients may experience. These symptoms can vary widely, depending on which areas of the brain are affected by the virus. Common physical symptoms include weakness or paralysis, difficulty walking, loss of coordination, and vision problems. Patients may also experience cognitive symptoms such as confusion, memory loss, and difficulty with speech and language. In some cases, patients may become comatose or completely unresponsive. Patients may be unable to work or perform simple tasks, such as dressing or feeding themselves. They may require assistance with activities of daily living, such as bathing and using the bathroom. In some cases, patients may require full-time care from a caregiver or a nursing facility.

In addition to the physical and cognitive symptoms, PML can also have a profound emotional impact on patients and their families. The diagnosis of PML can be devastating, especially since the disease is often fatal. Patients and their families may experience a range of emotions, including fear, anger, and grief.

Patients may also struggle with the uncertainty surrounding the course of PML and its outcome, which can be overwhelming for patients and their families. The emotional impact of PML can also extend to the patient's caregivers and loved ones. Caregivers may experience significant stress and anxiety, as they struggle to

provide the necessary care and support. They may also experience feelings of helplessness, frustration, and sadness.

It is important for PML patients and their families to work closely with their healthcare providers to develop a comprehensive care plan that addresses their individual needs and concerns. This may include regular check-ups and medication management. In patients recovering from PML, they may need physical, occupational, or speech therapy to manage their symptoms and maintain their quality of life. More in general, patients and their caregivers may benefit from counseling or support groups to help them cope with the emotional and practical challenges of living with a severe neurological disorder.

Emotional support: how to cope with feelings of anxiety, depression, and isolation.

Receiving a diagnosis of PML can be a devastating experience for both patients and their loved ones. The disease can have a significant emotional impact, including feelings of anxiety, depression, and isolation. Coping with these emotions is an important aspect of managing PML and maintaining quality of life.

It's important to remember that these feelings are normal, and you are not alone in experiencing them.

Here are some strategies you can try to help cope with these emotions:

Seek professional help: One of the most effective ways to cope with feelings of anxiety, depression, and isolation is to seek the help of a mental health professional. This may include a therapist, psychologist, or psychiatrist. A mental health professional can provide a safe and supportive environment to discuss your feelings and develop coping strategies. They may also be able to recommend medications or other treatments to help manage symptoms. They can provide you with personalized advice and support. One essential aspect of emotional support is understanding the emotions and recognizing the triggers that may exacerbate them. By identifying the source of anxiety, depression, or isolation, individuals can take steps to alleviate them.

Join a support group: Joining a support group of PML survivors can help you connect with people who have similar experiences. You can share your thoughts and feelings with people who understand what you are going through. Support groups can also provide a sense of community and

belonging, which can help reduce feelings of isolation. Social support is also crucial in managing emotions. Engaging in positive social interactions, whether through friends, family, or support groups, can provide individuals with a sense of belonging and connection. This connection can help individuals feel less isolated and provide them with a supportive network to turn to during difficult times.

Self-care: Taking care of one's physical, emotional, and mental well-being can help individuals feel better equipped to manage their emotions. Self-care can include activities such as exercise, spending time outdoors, and engaging in hobbies or interests. Mindfulness is a type of meditation in which you focus on being intensely aware of what you're sensing and feeling in the moment, without interpretation or judgment. Practicing mindfulness involves breathing methods, guided imagery, and other practices to relax the body and mind and help reduce stress.

Stay connected with friends and family: It's essential to maintain social connections with friends and family members. Even if you can't meet them in person, you can still stay in touch through phone calls, video chats, or text messages.

Educate yourself: Learning as much as you can about PML, and its management can help you feel more empowered and in control. Talk to your healthcare provider about your options for treatment and symptom management and stay informed about any new developments in PML research.

Nutrition, physical activity, and other interventions.

PML can have a significant impact on physical health, including mobility and coordination. However, it is important for PML patients to maintain a healthy and active lifestyle as much as possible to support overall health and well-being. Here are some examples of strategies that may be helpful:

Work with a healthcare provider: PML patients should work closely with their healthcare provider to develop a personalized plan for nutrition and physical activity. This may include recommendations for specific dietary modifications or exercise programs that are safe and appropriate given their individual symptoms and limitations. Nutrition plays a crucial role in maintaining a healthy lifestyle after PML. A balanced diet can help strengthen the immune system and aid in the recovery process. Dehydration can exacerbate symptoms of PML, so it is important to stay well-hydrated. Drinking plenty of water and other fluids throughout the day can help prevent dehydration and support overall health.

Engage in gentle exercise: While strenuous exercise may be difficult or impossible for PML patients, gentle exercise can still provide significant benefits. It can improve cardiovascular health, muscle strength and flexibility, balance, and coordination, as well as enhance mood and cognitive function. improve, maintain, and boost mood and cognitive function. However, it is important to start slowly and gradually increase activity levels, as excessive exercise can exacerbate symptoms and cause fatigue.

Physical therapy: It focuses on improving motor skills, coordination, balance, strength, and overall functional abilities. The specific approach may vary depending on the

individual's symptoms, level of impairment, and stage of recovery. Two commonly used approaches in neurorehabilitation are the Bobath Concept and Functional Movement Reeducation. Bobath Concept emphasizes the facilitation of normal movement patterns and postural control. It aims to promote the relearning of motor skills and functional abilities by addressing issues such as muscle tone, alignment, balance, and coordination. The focus is on improving movement quality and optimizing function through specific handling techniques, therapeutic exercises, and functional activities. Functional Movement Reeducation focuses on enhancing functional movement patterns to improve activities of daily living. It involves task-oriented activities and exercises that are designed to replicate real-life movements and challenges. The therapist helps the individual develop strategies to compensate for any physical limitations and regain independence in functional tasks. It's important to remember that therapy approaches are not mutually exclusive, and elements of both may be incorporated into a treatment plan depending on the individual's needs. The choice of physical therapy approach should be determined by a skilled physical therapist or rehabilitation specialist who can evaluate the individual's specific needs, goals, and functional abilities. They will be able to tailor the treatment plan accordingly to optimize recovery and functional outcomes.

Other supportive therapies: Speech therapy, and cognitive rehabilitation may be recommended as part of a comprehensive rehabilitation program for PML survivors. PML can also affect a person's language skills and cognitive abilities, leading to difficulties with understanding and expressing thoughts, memory problems, and reduced problem-solving

skills. Speech-language pathologists (SLPs) work with PML survivors to target these areas through various techniques, such as structured and individualized exercises language exercises, memory training, and cognitive-linguistic therapy. These interventions aim to improve overall language and cognitive function. PML can affect the muscles involved in swallowing, leading to dysphagia, or difficulty swallowing. SLPs assess and treat swallowing difficulties, developing personalized swallowing exercises and strategies to improve safety and efficiency during eating and drinking. The speech pathologist works in collaboration with the neuropsychologist to manage language and cognitive impairments, including language, long-term memory/working memory, problem solving and behavior planning- as a team.

Strategies for daily living: tips on how to manage practical difficulties and keep independent.

PML can present a range of practical difficulties that may impact a patient's ability to carry out daily tasks and maintain independence. However, there are strategies and tips that can help manage these difficulties and promote independence. The strategies presented here are based on the experiences of PML survivors and the advice of healthcare professionals.

Here are some examples:

Modify the home environment: PML survivors may need to adjust their home or work environment to accommodate their physical or cognitive challenges. Modifying the home environment can help make daily living tasks easier and safer. For example, installing grab bars in the bathroom, removing clutter, and arranging furniture to provide clear pathways can all help reduce the risk of falls and make it easier to move around.

Establish a routine: Survivors may experience fatigue and other symptoms that make it difficult to maintain a regular routine. However, having a routine can help to manage fatigue and make it easier to plan daily activities. This may include setting a regular time for meals, taking medication at the same time each day, and scheduling rest breaks throughout the day. It is important to set realistic goals and break tasks down into manageable steps.

Simplify tasks: Simplifying tasks can help make them easier to manage. For example, using pre-cooked or frozen meals can help reduce the time and energy required for meal

preparation. Additionally, breaking larger tasks into smaller, more manageable steps can help make them less overwhelming.

Use assistive technology: There are many tools and devices available to help PML survivors manage practical difficulties. For example, voice-activated assistants can help with tasks such as setting reminders, making phone calls, and controlling home appliances. Mobility aids, such as wheelchairs and walkers, can help with physical challenges.

Stay organized: PML survivors may experience cognitive challenges such as memory loss or difficulty with attention and concentration. It is important to use strategies such as writing things down, using calendars, and breaking tasks into smaller steps to help manage these challenges.

Seek help from others: PML patients may need help with certain tasks, and it is important to be willing to ask for and accept help from others. This may include family members, friends, or professional caregivers. Additionally, there are resources available to help connect patients with support services in their community.

Maintain social connections: Maintaining social connections is important for both emotional and practical support. This may include staying in touch with family and friends, joining support groups, or participating in social activities that are safe and manageable.

PML survivors can manage practical difficulties and maintain their independence with the right strategies and support. By implementing these strategies, PML survivors can live fulfilling lives despite the challenges they may face.

Caregiving overload: how caregivers can manage stress and maintain their mental and physical health.

Caring for a loved one with PML can be a rewarding experience, but it can also be challenging and stressful. Caregivers may experience physical and emotional exhaustion, sleep disturbances, depression, and anxiety, among other difficulties. It is important for caregivers to prioritize their own mental and physical health to provide the best possible care for their loved one.

One of the main causes of caregiving overload is the sheer amount of time and energy that caregiving requires. Caregivers often find themselves overwhelmed by the demands of caring for a loved one, which can lead to physical exhaustion and emotional burnout. Additionally, caregivers may feel a sense of guilt or responsibility for their loved one's condition, which can exacerbate their stress levels.

To manage stress and maintain their mental and physical health, caregivers can take a variety of approaches. One of the most effective strategies is to seek support from others. This may include joining a support group, reaching out to friends and family for help, or hiring a professional caregiver to provide respite care. Support can also come in the form of counseling or therapy, which can help caregivers address their emotional needs and cope with the challenges of caregiving.

In addition to seeking support, caregivers can also take steps to prioritize their own health and wellbeing. This may include practicing self-care activities like exercise, meditation, and relaxation techniques. Caregivers should also ensure that they are getting enough sleep and eating a healthy diet, as both factors can impact their physical and mental health.

Another important strategy for managing caregiving overload is to set boundaries and establish realistic expectations. Caregivers should communicate their needs and limitations to their loved ones and develop a plan for sharing caregiving responsibilities. This can help reduce the feeling of being overwhelmed and allow caregivers to focus on their own wellbeing.

Finally, caregivers should also be aware of the resources available to them. There are many organizations and programs that provide support and assistance to caregivers, including respite care, financial assistance, and legal advice. Caregivers should explore these resources and take advantage of them when needed.

Here are some strategies for managing stress and maintaining health:

Seek support: Caregivers should seek support from family members, friends, or support groups. It is important to have someone to talk to about the challenges and stress of caregiving, and to have people who can provide practical help as needed.

Take breaks: Caregivers should take regular breaks to rest, relax, and engage in activities they enjoy. This may include taking a walk, reading a book, or participating in a hobby. Taking breaks can help reduce stress and prevent burnout.

Stay healthy: Caregivers should prioritize their own health by eating a balanced diet, getting enough sleep, and engaging in regular physical activity. These strategies can help manage stress and improve mood and overall health.

Stay organized: Caregivers should stay organized by keeping track of appointments, medications, and important

information related to their loved one's care. This can help reduce stress and ensure that important tasks are not forgotten.

Communicate with healthcare providers: Caregivers should communicate regularly with healthcare providers to stay informed about their loved one's condition and treatment plan. This can help caregivers feel more confident in their ability to provide care and reduce stress related to uncertainty or lack of information.

Consider respite care: Respite care provides temporary relief for caregivers by allowing them to take a break from caregiving responsibilities. This may involve hiring a professional caregiver, enlisting the help of family members or friends, or utilizing a respite care facility.

Caregiving overload can have a significant impact on caregivers' mental and physical health. By seeking support, practicing self-care, setting boundaries, and utilizing available resources, caregivers can ensure that they are able to provide care for their loved ones while also taking care of themselves.

A community of support: how to connect with others living with PML and find online and offline resources.

While the medical community has made significant strides in understanding and treating PML, many patients and their families still struggle to find the resources and support they need to manage this challenging condition.

Being diagnosed with PML can be a lonely and isolating experience. However, there are many online and offline resources available that can help patients and their families connect with others living with the disease and find support.

Here are some examples of how to find support:

Join online support groups: There are online support groups for patients and families living with PML. These groups can be found on social media platforms such as Facebook, or on specialized health websites. They can provide a safe and supportive environment for people to share their experiences, ask questions, and find resources. Online forums, such as patient-focused websites, can provide a platform for patients and families to connect with each other and share information and support. Some online support groups may be specifically tailored to individuals with PML, while others may be more broadly focused on neurological conditions or rare diseases. Whether online or offline, a community of support can provide invaluable resources, advice, and emotional support for those who are dealing with the impact of this disease.

Connect with local resources: Local resources, such as community centers or hospitals, may offer support groups or other resources for people affected by PML. These resources

can provide a more personalized and local experience and can connect patients and families with others in their community who are going through similar experiences.

Attend conferences and events: Conferences and events, such as those organized by advocacy organizations or healthcare providers, can provide opportunities for patients and families to connect with each other and learn about the latest research and treatments related to PML.

Advocacy organizations: They can be a great resource for individuals with PML and their families. These organizations work to raise awareness about PML, provide education and support for patients and families, and advocate for research and treatments. The National Multiple Sclerosis Society, for example, provides resources and support for individuals with PML and their families, as well as funding for research into the disease.

Healthcare providers: In addition to support groups and advocacy organizations, individuals with PML and their families may also find helpful resources through their healthcare providers. Neurologists and infectious diseases specialists who are familiar with PML can provide information and advice about managing the disease, as well as referrals to other resources and support services.

Finding a community of support can be a crucial part of managing PML. Whether online or offline, connecting with others who are facing similar challenges can provide invaluable resources, advice, and emotional support for individuals with PML and their families. By seeking out these resources and making connections with others, individuals with PML can build a network of support.

Facing the future: how to manage uncertainty and change in post-PML life.

Recovery from PML can be a slow and unpredictable process, and many patients face uncertainty and change as they navigate life after the disease.

One of the primary challenges facing PML survivors is uncertainty about their future. PML can cause significant cognitive and physical impairments, and there is often little predictability in terms of how these impairments will progress. This can lead to feelings of anxiety, depression, and hopelessness. Experts suggest that PML survivors can manage uncertainty by focusing on the things that they can control, such as their daily routines and activities. They also suggest seeking out information and support from healthcare professionals, support groups, and other resources.

Another challenge facing PML survivors is adapting to change. Many survivors experience changes in their relationships, work, and overall quality of life because of their illness. Experts suggest that PML survivors can adapt to change by setting realistic goals and expectations, focusing on their strengths and abilities, and seeking out new opportunities for growth and learning. They also suggest developing a strong support network of family, friends, and healthcare professionals.

Managing uncertainty and change in post-PML life requires a multifaceted approach that addresses both the physical and emotional aspects of the survivor's experience. PML survivors should seek out information, support, and resources to help them adapt to their new reality, set realistic goals, and focus on their strengths and abilities. With the right tools and strategies, PML survivors can face the future with hope and resilience.

This is Russell, long term PML Survivor:

“My early symptoms were slight weakness in my left hand and numbness. It was diagnosed as a pinched nerve. I then began getting headaches, stomach issues, and balance problems. I went to a neurologist, and he diagnosed PML. I then progressively got worse until I fell at my parents’ house and couldn't get up. I was hospitalized and deteriorated very quickly. I had a spinal tap and brain biopsy, and both were inconclusive.

My HIV Dr continued meds and said hopefully if the meds controlled the virus, the PML would become manageable. I was put in a nursing home and given PT. I was unable to take care of myself and put on hospice care. They stopped my PT because the nursing home Dr told the insurance company that I was not going to survive. My HIV Dr tried to get me back on PT but couldn't. I feel this is why I still have major issues with my left side.

A couple of months in the home I started showing improvement and my parents took me home. My mother fought to get me PT once I went on Medicare and I was able to improve to the point that I needed the wheelchair less in the home.

Over the next 20+ years I continued to make strides and I now drive, live alone, and only use a walker when in public. I'm not going to say I wouldn't change a thing because that would be a lie, but going through this made me realize how strong I am and what is important in life. I'm more in tune with my body and mind. I don't stress out over everything, but don't ignore what I feel is wrong. I've also realized the importance of friends that will listen to me when I'm scared and when I'm happy. This experience has been equal parts hell and self-discovery.”

Hope and the future of PML research.

Despite advances in diagnosis, treatment, and management, PML remains a challenging disease. However, there is hope for the future of PML research as advancements in technology and understanding of the virus continue to evolve.

Several studies are on their way on several countries, aiming to better understand the mechanisms leading to PML, risk factors, optimizing diagnosis and exploring new treatment approaches. For example, in the U.S., there is the natural history of PML at NIH (NCT01730131). It doesn't involve treatment, but provides free access to experts at NIH, who will monitor the patient's prognosis, and keep them in the loop when any new treatments or trials emerge.

The most important and urgent area of research and intervention is the development of new treatments for PML. Currently, there is no cure for PML, and treatment options are limited. Researchers are studying the mechanisms of JC virus reactivation and the factors that contribute to the development of PML, with the goal of identifying new targets for therapy.

Overall, while PML remains a challenging disease, there is hope for the future of PML research. Advances in the understanding of the pathogenesis of PML are paving the way for improved patient outcomes. As research in this field continues to evolve, there is a growing optimism that we will find new and better ways to diagnose, treat, and ultimately cure PML.

Resources

Social media

www.facebook.com/PMLSurvivorsSupporters

www.facebook.com/groups/pmlsurvivors/

Online resources

ClinicalTrials.gov- This is a US-based database of ongoing and completed clinical trials. ClinicalTrials.gov contains numerous trials related to PML, including trials of new treatments and vaccines.

NORD- National Organization for Rare Disorders. It is a US-based nonprofit organization that provides advocacy, education, and support for people with rare diseases and their families. NORD's mission is to improve the lives of people affected by rare diseases by accelerating research, promoting education and advocacy, and providing patient support services. NORD provides a variety of resources, including a Rare Disease Database with information about over 1,200 rare diseases, patient assistance programs, advocacy and policy initiatives, and educational resources for patients, caregivers, and healthcare professionals. NORD also collaborates with government agencies, industry partners, and patient advocacy groups to advance research and improve access to treatments for rare diseases.

National Institutes of Health (NIH) Clinical Center- The NIH Clinical Center is a research hospital in Bethesda, Maryland that conducts clinical trials on neurological disorders, including PML. Patients with PML may be eligible to participate in clinical trials at the NIH Clinical Center.

The Johns Hopkins PML Center- This is a US-based center that specializes in the diagnosis and treatment of PML. The center provides information about PML, including its symptoms, diagnosis, and treatment options.